



NKDEP

National Kidney Disease
Education Program

Patients/At-Risk Work Group Meeting

Wednesday, January 30, 2002

MINUTES

Present

Larry Agodoa
John Bower
Wendy Brown
Mary Clark
Ann Compton
Phylis Ermann

Mary Harris
Fred Hill
Linda Holomah
Tom Hostetter
Myra Kleinpeter
Janice Lea

Mimi Lising
Winnie Martinez
Charlene Melcher
Carolyn Mosley
Phyllis Payne
James Reed

Kris Robinson
Dori Schatell
Barbara Van Gorder
Susie Warner
Beth Witten

I. WELCOME AND INTRODUCTIONS

Tom Hostetter thanked the group for attending and started introductions around the table.

II. NKDEP OVERVIEW

Tom summarized the incidence, prevalence, morbidity and mortality of kidney failure in the United States with data from the U.S. Renal Data System (USRDS). His main points were: (1) kidney disease is a huge problem; (2) there are interventions to slow the onset and/or progression of kidney disease, and (3) we are not doing enough to prevent and manage kidney disease. Most people don't realize that kidney failure is more common than death from certain cancers. But Tom is optimistic that the course of kidney disease, like the course of cardiovascular disease, can be changed. Like an ocean liner, he says we won't turn kidney disease around quickly, but we can take hope from the successes of cardiovascular disease programs, which 30 years ago were where we are now. They have made tremendous strides and we can, too.

Mimi summarized recommendations from previous NKDEP meetings and current activities:

- The program aims to “reduce the incidence, prevalence, morbidity, mortality, and cost of chronic kidney disease in the United States” by increasing awareness among the public and health care providers and by developing partnerships to extend NKDEP's reach.
- Initially, NKDEP will develop interventions for African Americans at high risk for kidney disease and primary care providers in four pilot cities—Baltimore, Atlanta, Cleveland and Jackson, Mississippi.
- Ultimately, successful interventions will be launched nationwide, and the program will extend its reach to people already diagnosed with kidney disease, policy makers, payers and purchasers of health care, and employers.

- NKDEP is developing an exhibit, a compendium of materials on chronic kidney disease, and a website, all of which should be completed in the next several months.
- Work groups formed thus far: (1) Health Care Professionals, (2) Patients/At-Risk, and (3) Evaluation.

NOTE: A psychologist or behavioral or social scientist needs to be on the Patients/At-Risk Work Group.

III. INTERVENTIONS

Charlene led the discussion about (1) objectives, (2) the literature review, (3) audiences' beliefs, attitudes and behaviors, (4) possible messages, and (5) how we will evaluation the program's impact. Because we recognize that African Americans are as diverse as other racial and ethnic groups, NKDEP will work with its partners to develop a menu of interventions from which pilot sites may choose, depending on the resources and needs of individual communities.

Objectives

People at High Risk (Primary Lay Audience). Objectives for people at high risk are (1) increase the number of people who are screened for kidney disease, (2) increase the number of people who know the risk factors for kidney disease, (3) increase knowledge about the severity of kidney disease and (4) increase the number people talking with their physicians about kidney disease.

People with Kidney Disease (Secondary Lay Audience). Objectives for patients are (1) increase adherence to treatment plans, (2) increase the number of patients who discuss treatment options with their physician, and (3) increase awareness about the severity of kidney disease. Our goal is to prevent or slow progression to kidney failure.

Health Care Providers (Primary Professional Audience). Objectives for health providers are (1) increase kidney disease screening, (2) increase awareness of risk factors for kidney disease (e.g., an African American with hypertension or diabetes or a family member with kidney disease should raise a flag for the provider to recommend screening for kidney disease), (3) increase awareness that kidney disease can be treated effectively (many providers do not take kidney disease seriously because they feel that nothing can be done) and (4) increase number of providers making effective treatment recommendations for patients with kidney disease.

Literature Review

We are reviewing the research literature to better understand the current knowledge, attitudes, and behaviors of our lay and professional audiences so that we can develop targeted, effective interventions. The review will be distributed to the work group.

Important questions to be answered include:

1. How do cultural beliefs, attitudes, and behaviors such as those related to weight, diet and exercise increase the occurrence of kidney disease?
2. How can cultural beliefs, attitudes and behaviors help prevent the occurrence of kidney disease?
3. What are the beliefs, attitudes and behaviors, unique to each pilot-site, that affect the occurrence of kidney disease?
4. How can the unique social support systems within the African-American community be used to help promote health?
5. How does age or gender affect knowledge, attitudes or behaviors related to kidney disease?
6. How is screening for kidney disease perceived? Is it finding out that you'll become very sick? Is it finding out that you can make yourself better or keep from getting sick?
7. What are the motivators and barriers that prevent someone from being screened for kidney disease? Are these environmental, social or personal? Can these be positively impacted by a communication campaign?

The literature on knowledge, attitudes, and behaviors is relatively limited for kidney disease. To supplement what we learn through the literature review, we will be conducting **focus groups** with people at high risk for kidney disease, dialysis and transplant patients and family members, and health care professionals.

Audiences

People at High Risk. Our *primary audience* is people at high risk for kidney disease, starting with African Americans at least age 30 who have had hypertension or diabetes or both for at least 2 years or who have a first-degree relative on dialysis or with a kidney transplant.

NOTE: The work group supported targeting “close blood” (e.g., aunts and uncles), not just “first-degree,” relatives. The National Kidney Foundation’s Kidney Early Evaluation Program (KEEP) has expanded to screen aunts and uncles. Most participants also favored reaching African Americans as young as age 18 years, since many already have diabetes or high blood pressure or both by that time. In addition, they noted that at older ages people may already be entrenched in unhealthy life-styles and have early kidney disease. **Post-Meeting Note:** Wave I focus group participants were ages 25 to 65 years.

People with Kidney Disease. Our *secondary audience* is African Americans who have early kidney disease.

Health Care Providers. Primary care providers such as internists, family physicians, physician assistants, nurse practitioners, diabetes educators, OB/GYNs, urologists, nurses, nephrologists, and emergency room staff will be a *primary professional audience*.

To augment what the research literature has taught us about the health practices of African Americans, NKDEP will conduct *focus groups* to further assess this population's understanding of and behavior related to kidney disease. A second wave of focus groups will test the effectiveness of messages among African Americans who have hypertension, diabetes, or a family history of kidney failure.

NOTE:

- Focus on **people at lower socioeconomic and educational levels**. Even though people who have health care aren't always screened or receiving appropriate treatment for kidney disease, NKDEP should explore ways to reach people at lower socioeconomic and educational levels, especially since other programs are unlikely to.
- To address systematic, institutionalized problems, **educate providers**.
- Having people with kidney disease tell **their own stories** or testimonies might be an effective way to reach African Americans.
- Consider **socioeconomic factors** (education and income) when designing interventions. Well-educated people tend to take better care of themselves, regardless of their race.
- **African Americans** should participate in planning and developing materials **for African Americans**.
- Providers may contribute to the disparity between African Americans and other patients by ordering fewer screening tests for this population.
- Include **literacy** experts to help develop products.
- **One message will not fit** every African American.
- Ann Compton will send us the name of an **African American post-doctoral fellow** who worked with ANNA to develop a chronic kidney disease manual and might be willing to work with NKDEP.
- People are more likely to trust **messengers** who look and dress and talk like them.

Messages

People at High Risk. Possible messages include:

- If you are African American and have diabetes, high blood pressure, or a close relative with kidney failure, you are at high risk for kidney disease.
- Left undiagnosed and untreated, kidney disease can lead to kidney failure. When your kidneys fail, you can live with dialysis or a kidney transplant.
- Early detection is important. Talk to your doctor today. Ask if you should have your kidneys checked.
- Effective treatment can prevent and slow kidney damage.
- You won't know you have kidney disease unless you get tested.

NOTE: Fear-based messages can be powerful motivators and should be tested for kidney disease. Many African Americans fear and want to avoid dialysis, which they equate with death.

People with Kidney Disease. Possible messages for include:

- Effective treatment can delay or prevent kidney failure.
- You can keep your kidneys working.
- Talk with your doctor about treatment options.
- You can live well with kidney disease.

Health Care Providers. Possible messages include:

- Some of your patients are at greater risk for kidney disease:
 - People with diabetes
 - People with high blood pressure
 - People with a family history of kidney failure
 - African Americans with one or more of the above risk factors
- Screen your patients for kidney disease if they are at greater risk. Early diagnosis and treatment can delay or prevent kidney failure.
 - Estimate GFR from serum creatinine using a prediction equation.
 - Spot-check urine to determine the ratio of protein to creatinine.
- Help your patients maintain healthy kidneys.
 - Prescribe an ACE-inhibitor or angiotensin receptor blocker.
 - Monitor tight blood pressure control.
 - Monitor tight glycemic control.
 - Refer patients to a dietitian and recommend a low-protein diet.
 - Help patients stop smoking.

NOTE: Because most providers will not estimate GFR it should not be a message.

Evaluation

Process Evaluation. The preliminary plan is to conduct:

- **Media audits** to measure publicity about the program.
- **In-depth interviews** with key people at pilot sites to assess the impact of activities and materials.

Outcome Evaluation. The preliminary plan is to conduct baseline and follow-up telephone surveys to determine to what degree the program achieved objectives. At each site, we plan to survey:

- 400 people at-risk

- 100 patients
- 100 physicians

NOTE: The success rate for reaching African Americans in phone surveys is low. The group suggested ways to improve response:

- Tell potential participants about the survey beforehand.
- Have African American surveyors contact African Americans.
- Provide a 1-800 or 1-888 number for people to call, rather than calling them directly. Many people will not or cannot respond to cold-call telephone surveys, but a toll-free number they can use at their convenience puts them in control and costs them nothing.
- Provide incentives such as a modest payment or calling cards, especially appealing to people who do not own a telephone.

IV. STRATEGIC PLANNING

Attendees identified channels for reaching lay and professional audiences, barriers to improving health, and activities and products that might most effectively carry messages to each audience.

People At High Risk

Channels. The possibilities are vast.

1. **Face-to-Face.** Individuals whom the audience might trust and talk to about health issues include:
 - a. Beauty salon staff and barbers
 - b. Children, young and grown, are powerful influences on parents
 - c. Church members, ministers, health ministries
 - d. Emergency room and clinic personnel
 - e. Family, friends and neighbors (the message is that you and your family should be screened)
 - f. Local “heroes” or idols
 - g. Local TV and sports personalities
 - h. Nurses and nursing students in emergency rooms and health clinics
 - i. People of the same racial or ethnic background
 - j. People who have kidney disease or kidney failure
 - k. Pharmacists, prescription inserts
 - l. Teachers, especially coaches
 - m. Youth and community leaders (formal or informal)

NOTE: It will be important to the program’s success to identify credible sources—people who are trusted—in a given community, who are willing to educate others. A credible but misinformed source is no better and may be more harmful than an accurate source that isn’t heard. NKDEP may need to educate willing community

leaders, a process described as “training the trainers.” An “NKDEP Seal of Approval” might guide people to accurate sources of information such as Web sites.

2. **Groups.** Outlets that may extend NKDEP messages to groups of people include:

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| a. African American clergy | n. Baptist conventions |
| b. Black Family Reunions in Washington, D.C. | o. Family reunions |
| c. Military (pre-enrollment physicals) | p. Dialysis centers |
| d. Schools (sports physicals and parent/teacher associations) | q. Families of dialysis or transplant patients |
| e. Health clinics | r. Community gatherings |
| f. Sports figures at games or other events | s. Cable, utility, credit card bill inserts |
| g. Churches | t. Calling cards |
| h. Employers/office bulletin boards and pre-employment physicals | u. Transit cards |
| i. Organizations such as NAACP | v. Make-up (Fashion Fair) |
| j. Veterans' organizations | w. Video rental stores such as Blockbuster |
| k. Community organizations | x. Buses |
| l. Education programs tailored for families of kidney patients (using existing kidney programs, such as KEEP) | y. National Black Women's Health Project |
| m. On-line support groups (low priority) | z. Small churches with lower income, less educated congregation |
| | aa. Screening/community service programs through EMTs, fire department |

3. **Mass Media.** The work group identified radio and TV stations, magazines, newspapers, and other outlets:

- a. Radio stations--jazz, gospel, black-audience, talk, gospel formats
- b. Magazines such as *Ebony*, *Jet*, and *Heart & Soul*
- c. Television such as Oprah, Ananda Lewis' show, an ad during Jerry Springer's show, Soap opera story-line, BET
- d. Musicians, including Rap and Gospel artists
- e. Sporting events
- f. Media kit with ads, PSAs, articles
- g. Church bulletins

NOTE: The work group cautioned against relying on print media and recommended personal and verbal channels as the best. They were enthusiastic about Oprah, who they say is very credible among African Americans, and suggested that we write to Oprah about Linda Holomah and propose on-air screening for her, her staff and her audience.

4. **Community and Informal.** Participants considered places where the audience congregates and where we might capture their attention.

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| a. Fairs and expositions | j. Restrooms |
| b. Bingo | k. Malls |
| c. Bowling | l. Community centers such as YMCA |
| d. Sports leagues | m. Churches, bulletins |
| e. "Million Man March" or "For Sisters Only" gatherings, which appeal to the survival of the black family | n. Health clinics, fairs |
| f. Beauty salons, barber shops | o. Funeral parlors |
| g. Casinos and state lotteries | p. Fraternities and sororities |
| h. Fast food restaurants | q. Hospital Public Access TV |
| i. School systems, clinics | r. Masonic Lodge (in Jackson) |
| | s. Organizations that have existing programs |
| | t. African American Women on Tour |

NOTE: The work group emphasized that personal contact will be key to success.

The Best Channels. After discussing all possible channels in the context of the message, credibility, accessibility, and feasibility (cost and time), the group identified those that might be most effective at reaching a lay audience:

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| 1. Dialysis units and transplant programs | 8. Federal, state, and local governments reaching employees |
| 2. An "Oprah" in each community | 9. Tom Joyner's show on black radio (heard nation-wide) |
| 3. Churches/health ministries | 10. Churches |
| 4. Beauty salons and barber shops | 11. Restrooms |
| 5. Toll-free (1-800 or 1-888) information line for pre-recorded messages | 12. Local sports event |
| 6. Insurance and managed care organizations | |
| 7. Disease management organizations | |

Barriers. Meeting participants identified barriers to better health.

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| 1. Economic: Lack of insurance, or insured but can't afford medicines, deductibles, co-pays, and transportation to appointments & pharmacy; healthier foods are more expensive. | backgrounds, in part due to incidents like the infamous Tuskegee studies. |
| 2. Credible sources perpetuate inaccurate information | 6. Lack of culturally accessible information |
| 3. Inaccurate information from the Internet (an NKDEP "Seal of Approval" may guide people toward reliable information) | 7. Lack of African-American messengers |
| 4. Fear of: needles, test results, being denied health and life insurance, losing job when company discovers illness | 8. Cultural importance of food and acceptance of being overweight |
| 5. Distrust of the medical system and providers from other ethnic or racial | 9. Ineffective channels, such as print campaigns for some audiences (audiovisual is best for African Americans) |
| | 10. Lack of convenient screening locations |
| | 11. Lack of belief that health should be a priority |
| | 12. Lack of safe place to exercise |
| | 13. Lack of adequate time with doctors |
| | 14. Low literacy, education (general) |

15. Lack of knowledge about health and kidney disease

16. Intolerable side effects from medications and lack of awareness about alternatives
17. Denial (see fear above)

Activities and Products. The work group identified activities and products that would most effectively communicate messages to audiences.

1. **Speakers Bureau** for religious services, especially during Black-history month; school assemblies, community meetings
2. **Speakers kits** containing fact sheets and other useful products for the general lay public, community leaders, patients and family members
3. **Train-the-trainer kits** to be used by churches, patients and relatives, and others willing to be messengers.
4. **Audio/video** materials in dialysis units, transplant clinics, waiting rooms, and other public places to explain who is at high risk, how to be tested, what to ask your doctor.
5. Encourage health care providers in **dialysis centers** to talk about the increased risk of kidney disease in families. For example, perhaps **CMS** should establish **mandates** for the patient's care plan to address "have you talked to your family about kidney disease?"
6. Help people find credible **internet** sites, place Pop-ups on websites such as blackvoices.com, and sponsor chat rooms and news groups
7. Work with partners to develop and produce culturally sensitive **materials**

NOTE: Concentrate on face-to-face activities.

Potential Partners. Participants identified groups, organizations, and businesses that might provide expertise or resources for local or national activities:

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| 1. Industry | 15. American Association of Kidney Patients and chapters |
| 2. Managed care | 16. American Diabetes Association |
| 3. Dialysis clinics, through CMS | 17. American Heart Association |
| 4. Black sororities—Delta Delta Gamma, Chi Eta Phi | 18. American Kidney Fund, especially in Baltimore and Atlanta |
| 5. Black journalists, radio personalities | 19. Association of Christians and Jews |
| 6. Nurses, social workers, physician assistants, family nurse practitioners | 20. BET (Black Entertainment Television) |
| 7. Minority nephrology associations | 21. Congressional Black Caucus |
| 8. Black colleges (to recruit volunteers) | 22. International Society for Hypertension in Blacks |
| 9. Medical schools (students need to fulfill community service) | 23. National Baptist Convention |
| 10. National church groups | 24. National Health Services Corp. in Jackson, Mississippi |
| 11. Denominational churches and local chapters | 25. National Kidney Foundation and affiliates |
| 12. Urban leagues | 26. National Medical Association |
| 13. Professional societies | 27. T.D. Jakes (gospel) |
| 14. Famous people at risk | |
| 15. Multicultural organizations | |

Health Care Providers

Channels. Participants encouraged NKDEP to reach health care professionals:

1. **Face-to-Face.** Who do health care providers consult about treatment guidelines?
 - a. Other doctors in the same or different practices and specialties; for example, primary care physicians consult with nephrologists
 - b. Industry representatives (also a barrier because of biased and incomplete information)
 - c. Receptionists, nurses, managers in physicians' offices
 - d. Emergency room staff educators (via bulletins or staff meetings)
 - e. Case managers
 - f. Social workers
2. **Groups.** Where could NKDEP messages be delivered to reach groups of health care providers?
 - a. Annual meetings/conventions (presentations and exhibits to distribute hand-outs such as laminated pocket cards)
 - b. State and local medical society meetings
 - c. Journals
 - d. Websites
 - e. Cassette tapes for listening while driving
 - f. Hospital Recreational Outings (e.g., group trip to ski resort)
 - g. Local medical societies and departments of health
 - h. Hospital bulletin boards, lunchrooms, and rest-rooms
3. **Mass Media.** What radio, TV, Internet and print outlets reach health care providers?
 - a. Internet (PubMed, Merck, Hypertension, Dialysis and Clinical Nephrology (HDCN))
 - b. Journals
 - c. Employee newsletters
 - d. Professional newsletters
4. **Community and Informal Channels.** Which organizations and informal sources might communicate NKDEP messages to health care providers?
 - a. Continuing medical education
 - b. Staff restrooms (notices)

The Best Channels. Considering the context of the message, credibility, accessibility, and feasibility (cost and time), the work group said professional societies are the best channels for reaching this audience.

Barriers. What discourages health care professionals from changing their own practices or behaviors? What motivates them to change?

1. Motivators
 - a. Regulators (medical guidelines)
 - b. Industry representatives (negative aspect is that they present biased information)
2. Barriers
 - a. Fear that nephrologists will “take” patients
 - b. Lack of time
 - c. Denial of a problem
 - d. Attitudes, biases about African Americans affect decisions about what treatments will be offered

Activities and Products. What awareness and education activities and products will most effectively carry NKDEP messages to health professionals?

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| 1. Laminated pocket cards | 5. Programs to educate industry representatives |
| 2. Practical decision trees | 6. Programs to train office staff |
| 3. Fact sheets for patients (Why is kidney disease important and what can be done about it?) | 7. Manual or fact sheet for nurses |
| 4. Presentations at state and local medical society meetings | 8. Fact sheet for diabetes educators |
| | 9. CME programs that are convenient (on audio/videotapes, etc. |

Potential Partners. Who can NKDEP work with to influence change among health professionals?

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| 1. American Association of Office Nurses | 7. American Association of Cardiologists |
| 2. American Association of Diabetes Educators | 8. American Society of Hypertension |
| 3. American Association of Clinical Endocrinologists (consider for steering committee) | 9. American Society of Transplant Surgeons |
| 4. American Diabetes Association | 10. American Society of Transplantation |
| 5. American Dietetic Association | 11. Association of Christians and Jews |
| 6. American Academy of Family Physicians | 12. Insurance companies |
| | 13. United Way |
| | 14. Professional societies/associations (local chapters) |

V. NEXT STEPS

Focus Groups

Tom invited work group members to attend focus groups and asked for suggestions and changes to improve the moderators’ guides. Focus group results will be available around the end of March and will be sent to work group members. [ACTION]

Literature Review

We hope to complete the review in the next several months. We will distribute it to Patients/At-Risk work group members. [ACTION]

Evaluation

We are continuing to work with the evaluation work group to identify objective measures.

Tom closed the meeting by emphasizing that he wants to hear what participants think we should be doing, even after they return to their homes.

The meeting adjourned at 2 p.m.